

Gay & Bisexual Men's Project

Evaluation Report

January 2018

POSITIVELY UK

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Executive Summary

This report presents the findings of the evaluation of Positively UK's Gay & Bisexual Men's Project. The project was set up to provide support to gay and bisexual men living with HIV, a group who are vulnerable to stigmatization, isolation and lower levels of wellbeing. The project goal was to empower service users to successfully transition to effective self-management and independent living with HIV.

The project, commencing in June 2015, provides a range of one to one and group support interventions, delivered through a Gay Men's Project Co-ordinator and supported by a team of volunteer peer mentors. The evaluation was carried out at the end of year two of the three-year project, after 250 men had been supported. It was informed by quantitative and qualitative data, including an online survey completed by over 100 project participants.

Although HIV was found to be the main entry point into the services, there were numerous support needs beyond HIV. Many participants expressed mental health, social and economic needs that were either exacerbated by HIV or affected their ability to live with the condition.

The evaluation's key findings:

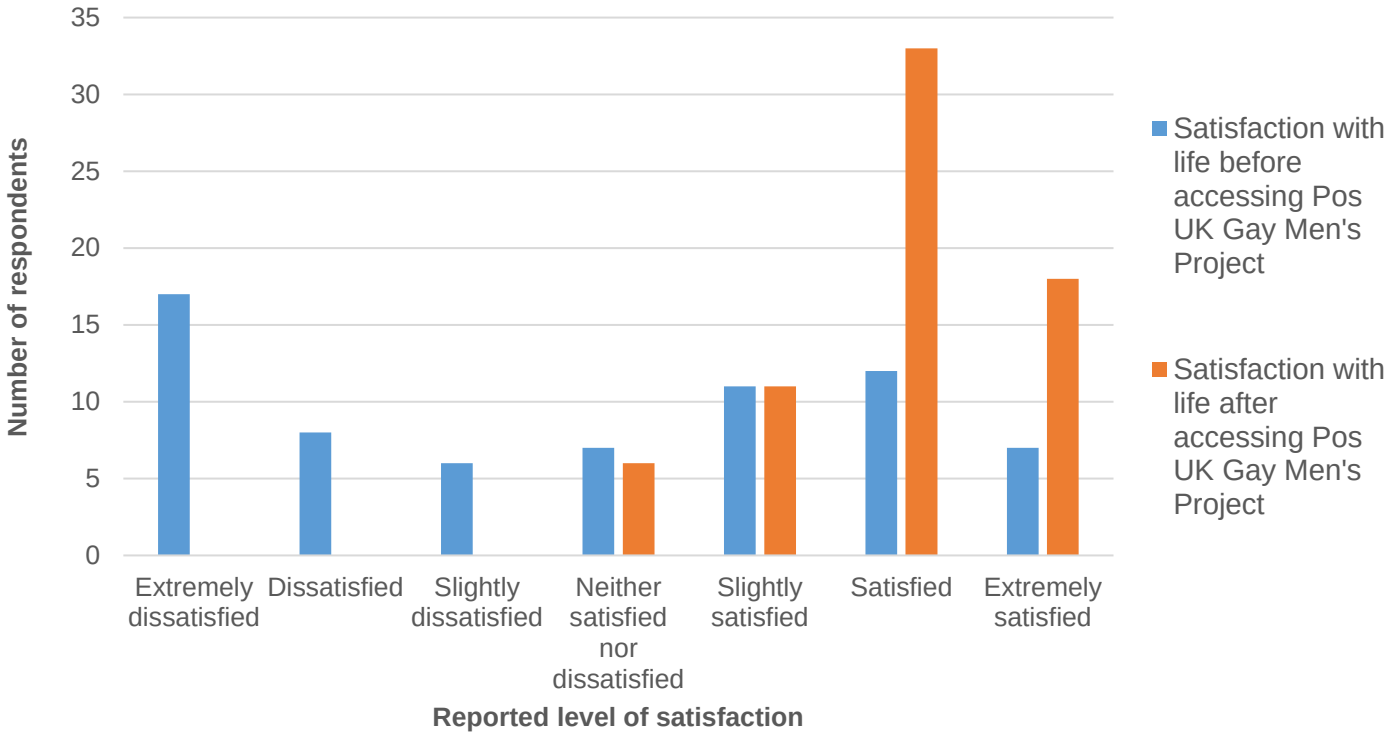
- the project improved people's ability to live with HIV as a chronic condition. For most, reported self-satisfaction with their life increased markedly after accessing the services (see Figure 1 below)

- provision of information by the project was a key component in helping many to deal with their emotional challenges and accept their status, this being gained more through trust in others lived experience, rather than scientific or medical knowledge

- social support provided by the Recently Diagnosed workshop, the GayTalk group and social networking stopped participants from feeling 'cut-off' and helped re-integrate them back into society

- project services helped those impacted by HIV stigma to normalize HIV and feel 'it's ok to be HIV positive' (participant 7, survey)

Figure 1. Satisfaction with life in general before and after accessing Positively UK's Gay Men's Project



"The services and opportunities provided by Positively UK's Gay and Bisexual men's project have been a powerful force for good in my post diagnosis life. Thanks in part to the project, along with my excellent medical teams, I am now undetectable, living happily with my negative partner, going from strength to strength in my job, participating in sports training, travelling abroad, and I rarely have to think about HIV at all… In fact, I don't think I've ever felt healthier or happier"

Participant 12, survey

The majority of participants showed a high level of satisfaction with the project. The following recommendations are made for future improvements:

- Continued funding in peer support for gay and bisexual men to help ensure that the large investments in medical care and treatment result in health outcomes that are sustained throughout the life of the patient
- Ensure project outcomes are closely aligned with user need, including additional research conducted into the needs of those under-represented in the evaluation such as those not in work and with lower levels of formal education
- More support provided around managing drug and alcohol use and smoking cessation
- Improved publicity of services offered by the project, particularly in clinics

The Needs of Gay and Bisexual Men Living with HIV In The UK

Gay and bisexual men often have to deal with perceived discrimination, anticipated rejection, internalized homophobia, low self-esteem related to poor self-image and concealment of sexual preferences. Consequently, many gay and bisexual men live with psychological distress, anxiety, depression and related health risks which can lead to HIV risk behaviours, and generally affects their wellbeing.

Advances in HIV treatment have led to huge improvements in the health and wellbeing of people living with HIV. However, HIV is a lifelong condition and in the UK is still perceived as a condition that mainly affects sexual minorities, for whom HIV stigma results in a higher risk of poor mental health.

The needs of gay and bisexual men living with HIV are therefore numerous and for many an HIV diagnosis acts as a catalyst to other emotional stressors. In addition, gay and bisexual men, cannot be treated as one homogenous group. There are variations in terms of ethnicity, educational background, economic/employment status, nationality, age, household situations and other individual differences which services need to account for.

Project Background

Positively UK's Gay Men's Project, funded by the Big Lottery Fund, started in June 2015. It was designed to empower gay and bisexual men to successfully transition to effective self –management and independent living with HIV. Its target included newly diagnosed individuals as well as those with support needs who had been living with HIV for several years.

The service is provided through a Gay Men's Project Co-ordinator, supported by a team of volunteer peer mentors, all client facing work being delivered by gay and bisexual men living with HIV. The main components of the project are:

- workshops for recently diagnosed people
- one to one mentoring
- Saturday GayTalk group
- GayTalk social events
- GayTalk Facebook page and WhatsApp group
- one to one advice and advocacy
- referrals to external agencies

By February 2017, when the evaluation was started, 250 men had accessed the project's services. Service users represented a wide variation in terms of age, length of diagnosis, employment status, ethnicity and country of birth. The majority of users identified as gay, with only a small number (11 people) identifying as bisexual.

Evaluation and Methodology

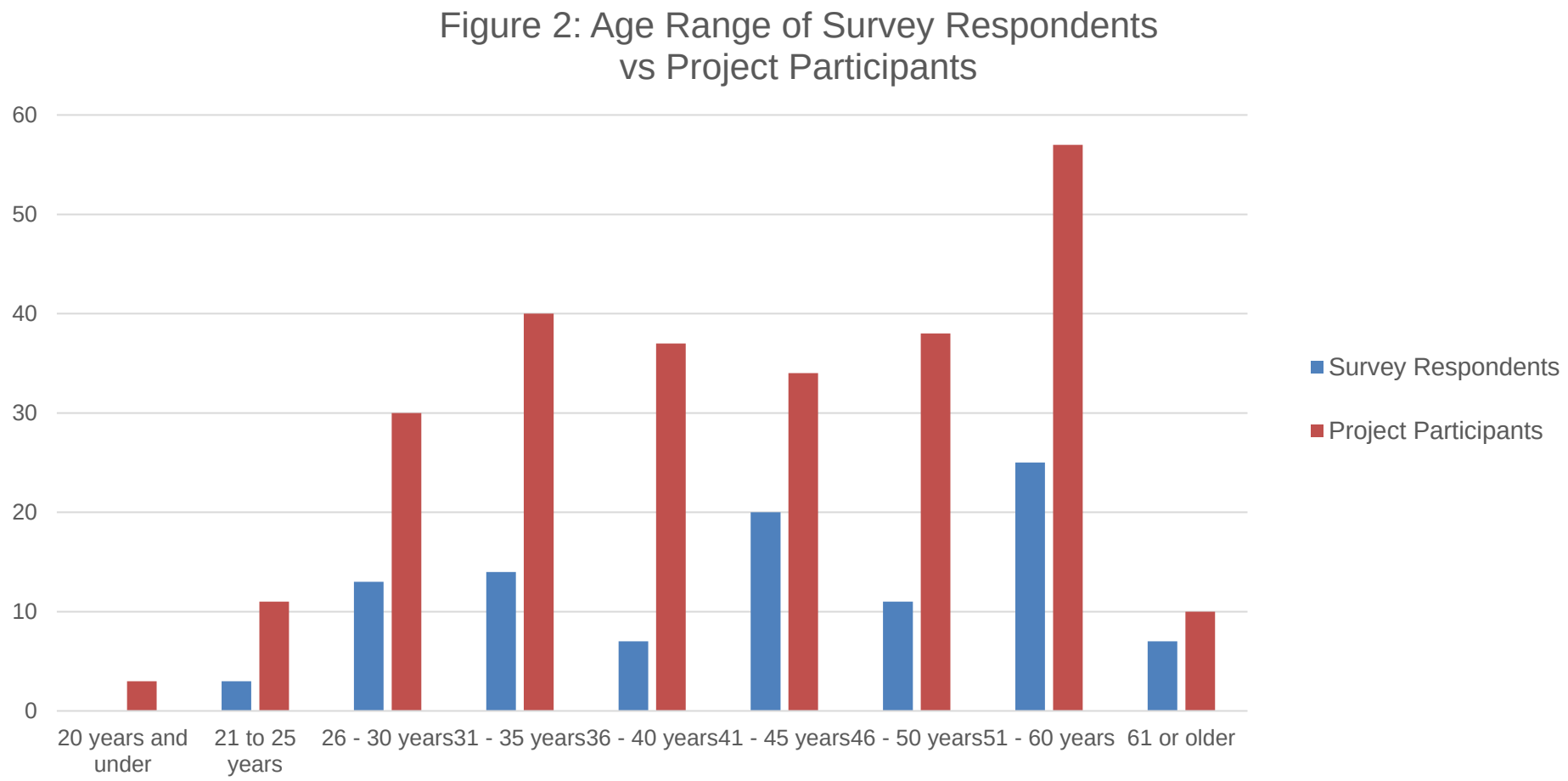
The purpose of the evaluation was to examine the effectiveness of Positively UK's Gay Men's Project in meeting the needs of gay and bisexual men. In particular whether the project and its component services:

- Increased the ability of project users to manage HIV as a long-term condition
- Supported the social inclusion of project users by reducing their isolation through increasing their social and support networks
- Increased the ability of project users who had problematic use of recreational drugs to manage or cease their drug use
- Increased the emotional wellbeing of project users enabling them to improve self-esteem around their sexuality and HIV status and to develop coping strategies for stress

The evaluation was carried out between February and June 2017 and was co-designed in consultation with key stakeholders from Positively UK staff, Trustees and service users. It was informed by quantitative and qualitative data obtained through an online survey, in-depth interviews, case studies and project monitoring data. A total of 101 men out of 250 who accessed the project responded to the survey, with the responses from 98 participants included in the analyses.

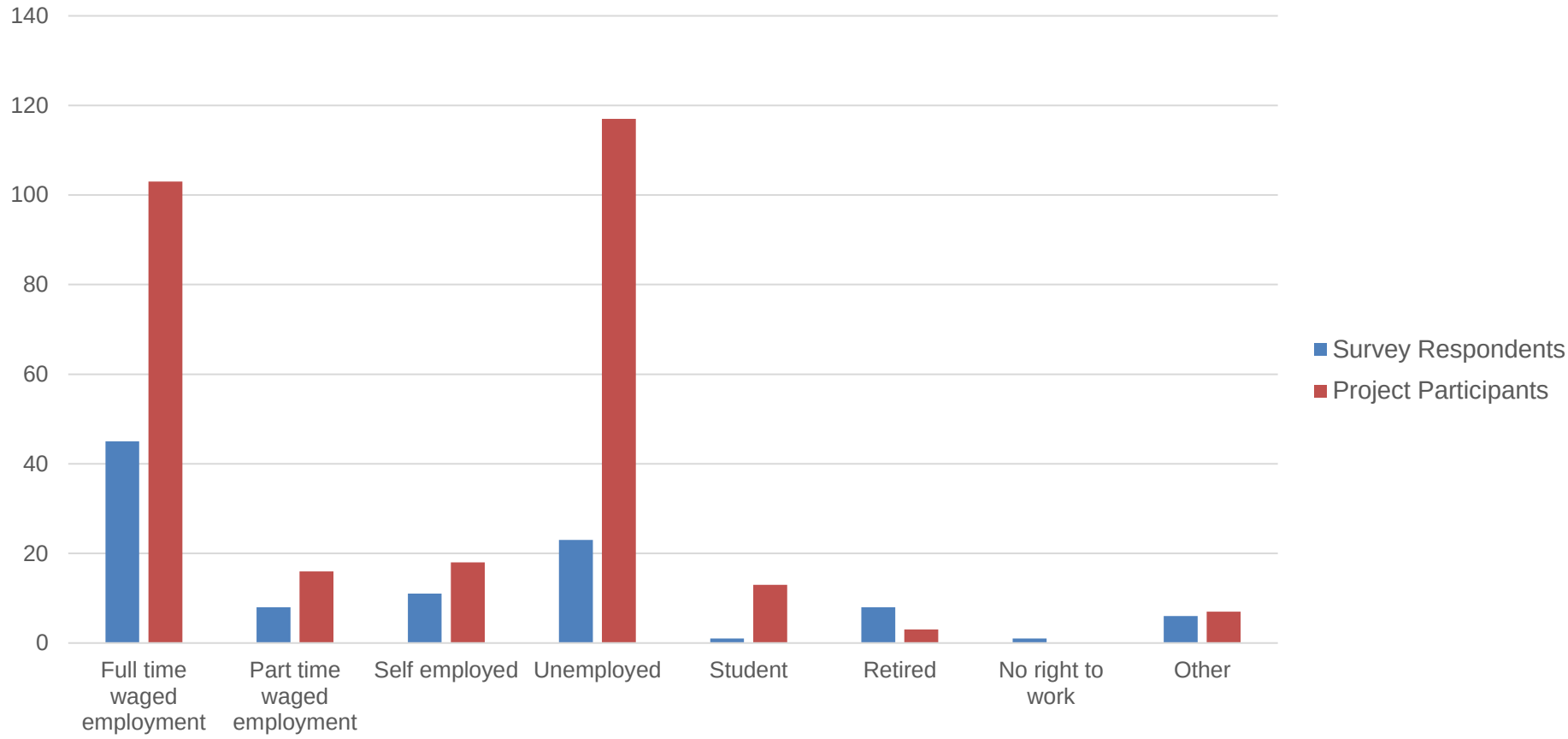
Survey Participant Demographics

Age: The project attracted men from a wide age range, and the survey participants also broadly reflected this. See Figure 2.



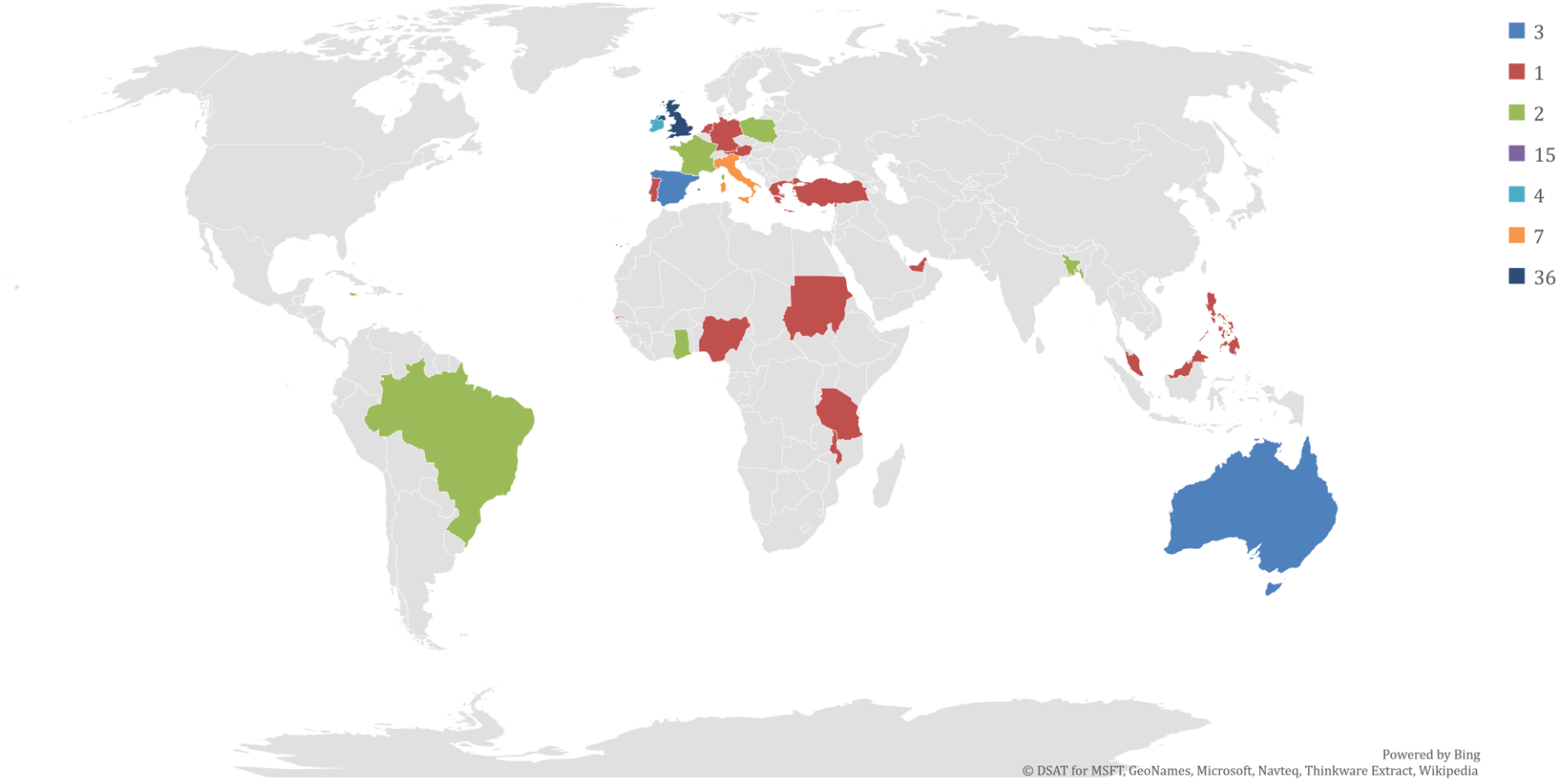
Employment Status: 34% of project users were in full-time salaried employment, with 45% unemployed and 13% working part time or self-employed. This contrasted with 45% of survey participants in full-time salaried employment with 23% unemployed. See Figure 3.

Figure 3: Employment status of Survey Respondents vs Project Participants



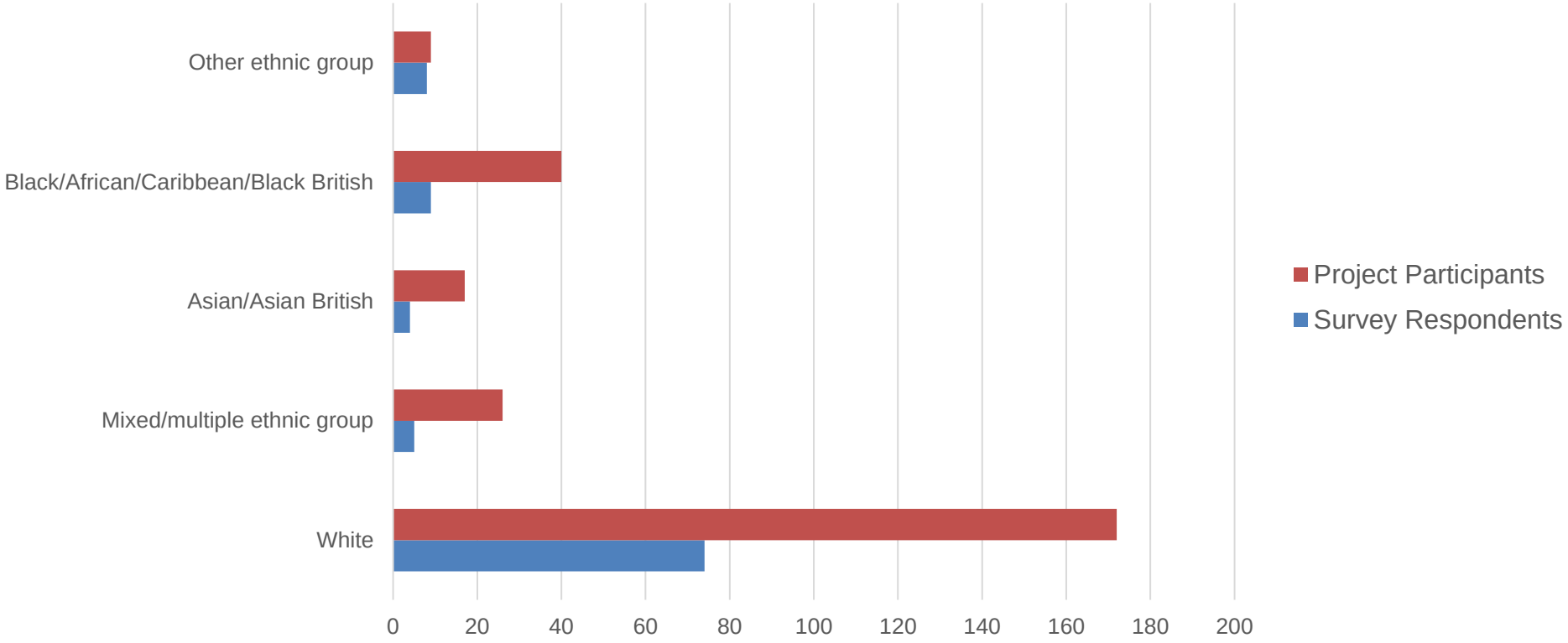
Country of Birth: A total of 53 countries were represented amongst project users, with just over one third (37%) born in the UK. This compares with 27 countries represented amongst survey participants, with just over half (54%) being born in the UK. See Figure 4.

Figure 4. Survey Respondents country of birth



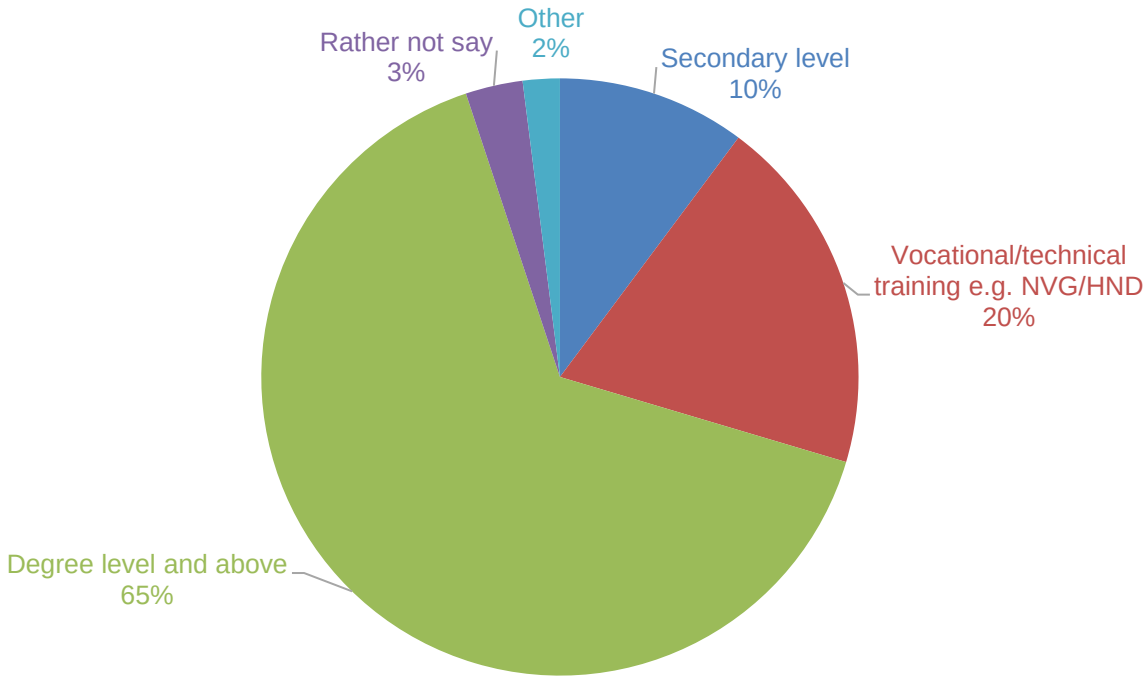
Ethnicity: 64% of project users identified as white (of these 27% British, 6% Irish, 31% non-British). 30% identified as from an ethnic minority (of these 10% Mixed, 6% Asian, 14% Black). This compared to 76% of survey respondents identifying as white and 24% identifying as from an ethnic minority. See Figure 5.

Figure 5: Ethnicity of Survey Respondents vs Project Participants



Education: The majority (65%) of survey participants had at least a bachelor's degree, followed by 20% who said they had vocational or technical training. Survey participants were therefore an educated sample with 85% having vocational qualifications and above. See Figure 6.

Figure 6. Educational Level of Survey Respondents



Length of time living with HIV: 42% of survey respondents were diagnosed HIV+ during the project, suggesting that the project was successful in attracting those recently diagnosed. Many of those accessing the project, including peer mentors, had lived with HIV for several years.

Service User Needs

Survey participants were asked around which issues they needed support when accessing the project. Some of these needs were not related to being HIV+ but were exacerbated by it. Expressed needs were grouped broadly into the following 4 areas:

Mental health concerns: Ongoing for some individuals but worsened by the stress of an HIV diagnosis. The service helped some individuals to move away from negative suicidal deliberations to being positive about the future.

The need for knowledge about living better with HIV: including around adherence to HIV treatment, healthy living and telling others about their HIV status

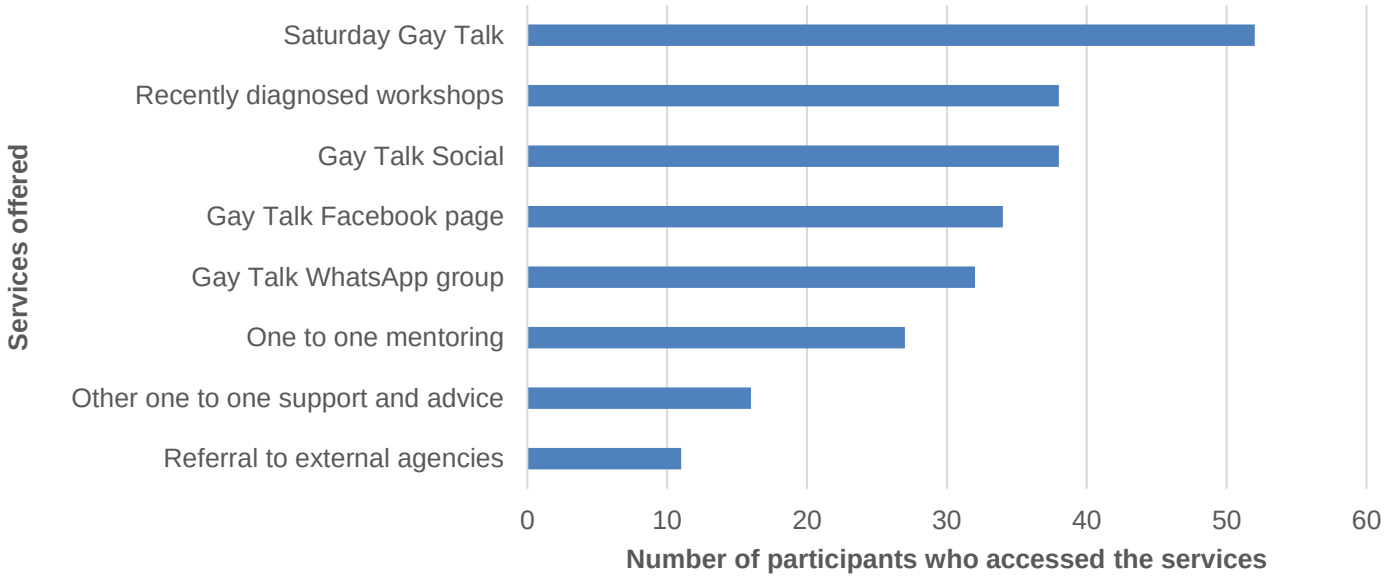
Social support: This was a major need expressed in terms of a desire to meet friends, to talk to someone or to meet people with similar challenges.

Financial needs: including support in securing welfare benefits and advice around housing concerns

Services Accessed

When asked which services participants accessed, Saturday GayTalk was the most popular service, followed by the recently diagnosed workshop and the GayTalk social. The recently diagnosed workshop was considered to be the most *useful* service.

Figure 7. Services accessed through Positively UK's Gay Men's Project

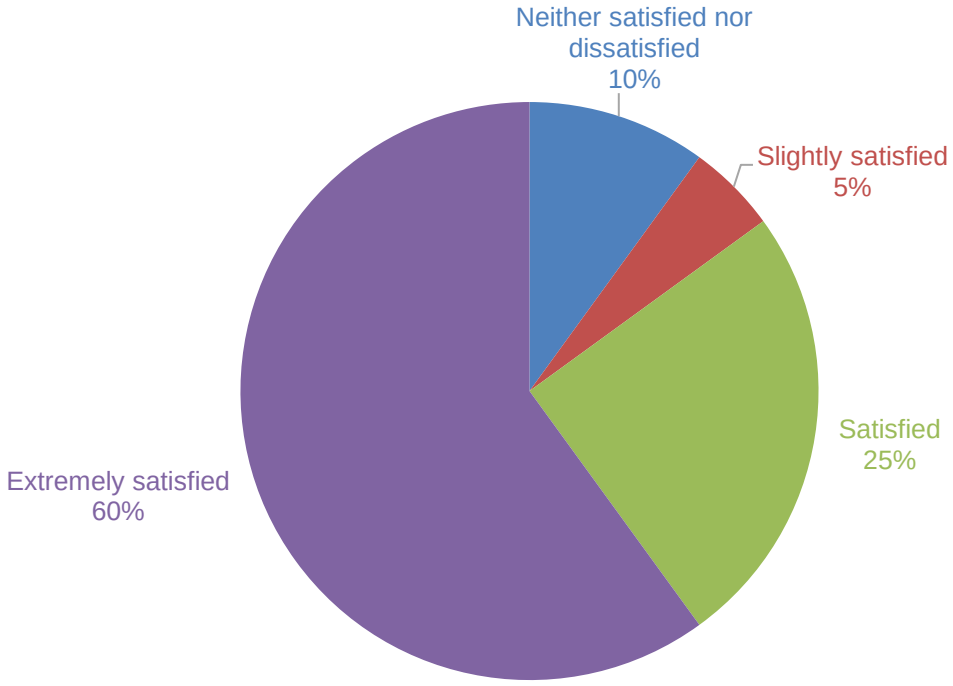


When asked whether participants believed their needs were being met by the services they accessed, 96% of those who responded to this question confirmed that services met their needs. Individuals in full time employment and with qualifications at degree level and above were more likely to feel their needs were being met.

Referrals to Other Services

65% of all referrals were made internally within Positively UK e.g. benefits advice. However, twenty participants surveyed said they had been referred to other services for support needs that could not be addressed by the organisation. These included GUM clinics, The Food Chain, counselling services, National Debt Line services and others. 85% of these respondees were either 'extremely satisfied' or 'satisfied' with these external referrals.

Figure 8. Satisfaction with External Referrals



Emotional Well-being

Emotional wellbeing was a huge concern for many participants, and for some men, poor mental health was a risk factor that had contributed to their HIV infections in the first place.

Some newly diagnosed individuals were yet to come to terms with their status and uncertainty around their long-term survival with HIV caused high levels of anxiety. Participants who had been living with HIV for longer (over 10 years) had accessed services (particularly GayTalk) to help them deal with HIV related depression and anxiety. Some participants reported harbouring suicidal thoughts and were glad of the support they had received through the project. A number of Peer Mentors expressed surprise and satisfaction in how their involvement in the project had helped to resolve personal issues they had previously packed away for many years.

Participants reported that access to the project made a difference to them in many ways. Some of the men spoke of having 'turned the corner' and being in a 'better place' emotionally after receiving information and support. One common theme, that helped many deal with their emotional challenges was *information*; helping them to face life more positively, to understand what they needed to do to improve their

quality of life with HIV and being more aware of available services should they need them. Having this information enabled individuals to better understand living with HIV, in turn better enabling them to accept their status.

> *"I feel much happier in my life. It's no longer the end of the world. I still need more [support] but I am getting there"*
>
> **Participant 9, survey**

The GayTalk group, for example, enabled some of the men to realize they were not alone because they knew where and to whom they could turn when they felt depressed or needed practical support. More importantly, some of the participants noted the fact the services offered through Positively UK covered issues beyond HIV, meant they received help with many of the catalysts of their emotional stressors.

Social Support and Social Networks (Social Inclusion)

The findings suggest that an HIV diagnosis signified *detachment* from the social network for some of the participants. They felt isolated from their social networks because they could not easily share their new status for fear of stigma. To ensure their confidentiality, they kept a social distance. For some, the fear was based on negative experiences; for others it was based on perceived risk of stigma. The social and networking components of the project offered a platform for participants to explore and share their identity as people living with HIV, something that was often not available to them with friends and family. Some of the men felt that accessing the project relieved the pressure on friends and family, who themselves may not be conversant with HIV issues, even if they were not actively stigmatizing in their support.

The project also provided an opportunity to get expert views on living with HIV through Saturday GayTalk and social events:

> *"You have information as an expert. A doctor who has information from reading books and scientific papers has no idea of what it means to live with HIV. But members of the support groups are experts. Sharing the information is giving back to the community – helping each other. Making each other stronger and better"*
>
> **Participant 4, peer mentor, interviews**

The above extract illustrates the importance of trust in experience over scientific knowledge. The safe space provided by Positively UK also enabled the men to ask

questions freely without worrying about being judged, and knowing the support they received was from people with similar experience who genuinely meant them well.

The groups also provided an opportunity to make friends, with the GayTalk events and, online Facebook and WhatsApp groups helping to formulate connections and friendships that would operate beyond Positively UK.

> *"It was refreshing to meet so many people living with HIV and to hang out in the GayTalk events, gay social and online forum… meeting even straight men and women and hearing their stories made me feel less isolated. I feel I am part of the society after all… I am also confident enough to manage my life with HIV and to manage my relationship with my friends better"*
>
> **Participant 1, interview**

The above extract illustrates perceived *re-inclusion* into society after accessing the project. These opportunities were also particularly important for non-British nationals with limited social networks in the UK.

The findings suggest that the project played a big role in enhancing social support and networking opportunities for the men involved. However, some respondents felt less confident in their ability to build relationships and were still vulnerable to exclusion because of this.

> *"I hoped to make some friends at GayTalk but haven't managed that yet. I'm still struggling to be myself and find it hard to talk to other people"*
>
> **Participant 26, survey**

Recreational Drugs, Alcohol and Smoking

Participants were asked about their experiences with recreational drugs, alcohol and smoking. About a quarter of those who responded to the question said they had used recreational drugs and 52% had either never used them or stopped completely. 23% were currently occasional or regular users. Over 80% of participants said they drank alcohol with varying frequency and 28% were regular drinkers. Almost a third (32.3%) were regular or occasional smokers.

The findings suggest that use of drugs, alcohol and smoking (whether regularly or occasionally) is prevalent among significant numbers of participants, although these

were lifestyles in many cases that had existed before the individuals were diagnosed with HIV. For some, an HIV diagnosis made such habits problematic because they became 'solace' from the stress of the diagnosis.

> *"I know I must stop… and I am working on it. I am getting help for it… I am not sure… I don't know if they [Positively UK] do anything drugs related… you quickly realize nobody is talking about drugs… you avoid mentioning your drug issues"*
>
> **Participant 7, interview**

This extract illustrates that recreational drugs were a problem, that the participant knew what he had to do and was already getting the support he needed. However, although men needing drug support were referred to more specialist external services, it seems this participant would have preferred more support from within the Gay Men's Project.

HIV Stigma

Stigma was the undercurrent in all the other themes from this evaluation. It was the fear of stigma that created social isolation and mental ill-health for some participants. HIV stigma was layered over participants other stigmatized identities such as sexual orientation or immigration status.

Despite the advances in effective treatment, HIV remains a highly stigmatized condition in UK society. As a result, the participants who worried about being stigmatized within their existing social networks, selectively disclosed or concealed their HIV status, based on their own assessment of the risk of exposure.

The findings suggest that the awareness and support the participants received from the project helped ease some of the misconceptions they had about HIV and they were able to 'normalise the disease' - a huge step towards managing HIV stigma. The normalization came through interaction with others in the same situation as well as the knowledge acquired through various services offered by the project.

> *"This [Recently Diagnosed] workshop and the 'Stigma workshop' saved my life, it empowered me to look at my diagnosis with a positive light and gave me the tools to face my diagnosis with confidence"*
>
> **Participant 20, Survey**

This extract outlines the impact of the services on the attitude of the participants towards life in general. For some, being diagnosed HIV positive made them feel different (internalized or anticipated stigma) and accessing the project made them understand *'it's OK to be HIV positive'* (Participant 7, survey).

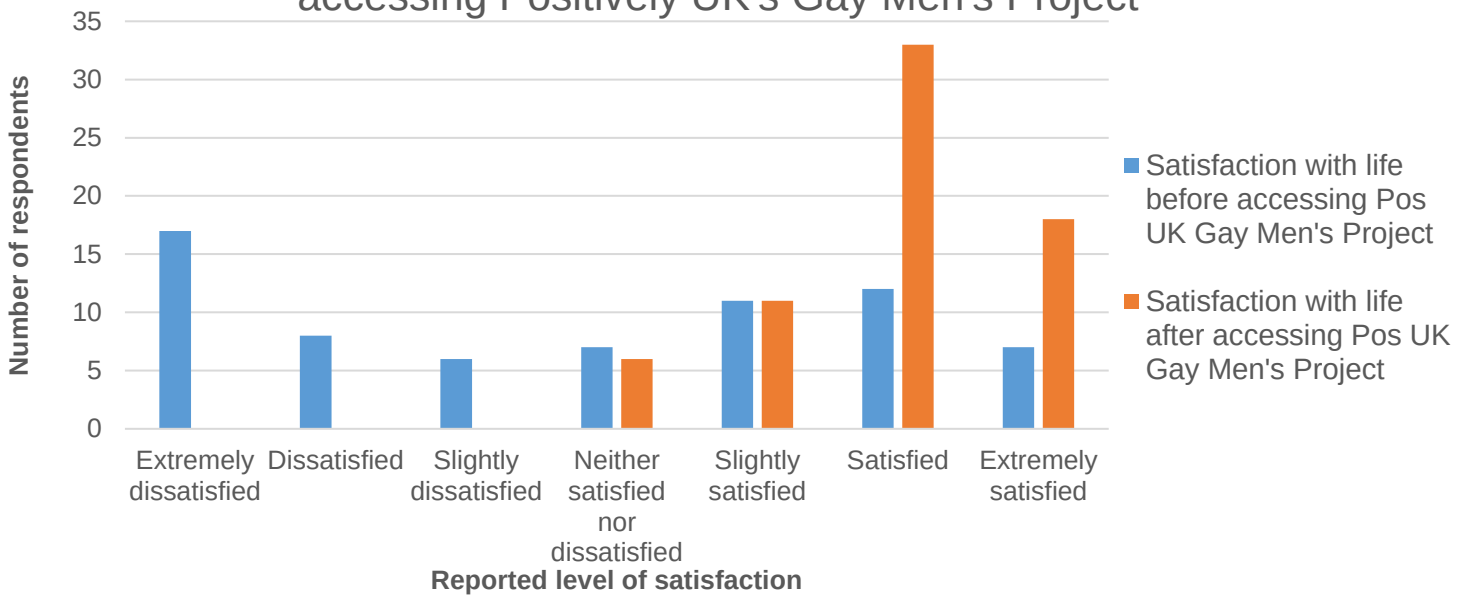
Managing HIV As a Long-Term Condition

The support offered through the Gay Men's project empowered the service users both individually and as a social group to better manage life with HIV. As individuals they learnt how to deal with practical things such as adherence, a healthy diet and disclosure of HIV status. They also received support with housing and welfare benefits. As a social group, the services created a community of individuals with related needs who were happy to share their experiences of living with HIV. Those interested therefore engaged in group and social events provided by the project such as Saturday GayTalk and GayTalk socials.

Satisfaction with Life in General

The overall goal of the project was to empower service users to live as best they can with HIV. One of the key questions the participants were asked was how satisfied they were with life in general after accessing the services offered through the project, compared with before they used the services. Even though there was no baseline data with which to compare reported satisfaction, the participants responses showed that they felt more satisfied with life after using the services.

Figure 9. Satisfaction with life in general before and after accessing Positively UK's Gay Men's Project



Case studies

Case Study 1: Joe (not real name)

Joe is a young British gay man who was diagnosed with HIV three years ago. He first accessed the project through attending a Recently Diagnosed workshop, but went on to attend the GayTalk group and access the GayTalk Facebook page and WhatsApp group.

The workshop gave Joe a clear understanding of his condition which was essential is combatting his fear. It also allowed him to meet other people in the same situation and to see them living happy, healthy, normal lives – which provided enormous re-assurance. The course also empowered Joe to transfer his HIV care to a better clinic. Subsequently attending the GayTalk group helped grow his knowledge and build new friendships, as well as giving him the confidence to start dating again.

Joe is now successfully dating and feels able to move on from the group now that he has the knowledge and confidence to live well with HIV. He also feels that the skills he has gained are adaptable to many areas of his life and have also had knock on effects in terms of better relationships with family members.

Case Study 2: Neville (not real name)

Neville is a 56-year-old British gay man who has lived with HIV for 16 years. He first accessed the project in June 2015 looking for support as he had lost a lot of confidence. His disability and use of a wheelchair made it difficult to develop and maintain social networks. Neville was assigned a peer mentor.

Having a mentor helped Neville take better care of himself and gave him the confidence to come to the Saturday GayTalk group as he could come with someone he knew. Neville had found a group where he could be himself with no judgement or rejection. Since the mentoring has come to an end, he has trained to become a peer mentor himself and helps others with their HIV at GayTalk where he is one of the regulars.

Neville also accessed support around his benefits as he was finding changes around his entitlements very stressful. Positively UK's Benefits Advisor helped with form filling and attending assessments.

Recommendations

Overall, the majority of participants showed a high level of satisfaction with the structure and content of services offered through the Gay Men's project. The following recommendations are made for future improvements:

Need for continued funding

A key finding from this evaluation is the positive impact the services have made on the users. Participants said that the project played an important supplementary role to clinical care, often relieving the burden on clinics by providing the crucial link between diagnosis/treatment and living healthily with HIV. Continuing to fund this service will help ensure that these large investments in treatment result in health outcomes that are sustained throughout the life of the patient. Without effective peer support for people living with HIV, treatment success and improved wellbeing may not be achieved.

Ensure project outcomes are closely aligned with user need

The evaluation showed that user needs are grouped into 4 key pillars: mental health concerns, the need for knowledge about living better with HIV, social support and financial needs. Moving forward, the project should ensure that its focus remains on meeting these needs.

Additional research into the needs of under-represented users

Data from the evaluation showed that those not in employment and with lower level educational qualifications were under-represented in the survey respondents. Additional research is therefore needed to determine user need within these demographic groups.

Structure of the services

Service users liked the fact that they could choose which components of the service they felt were most suited to their needs. One key strength of the Recently Diagnosed workshop was its focus on knowledge and practical advice, and that this should be maintained. Some participants felt that there needed to be more support around drug and alcohol use, or at least a culture of support further developed where these issues could be discussed more openly. Given that one-third of participants are smoking, some smoking cessation support could also be introduced.

Publicity

Some participants suggested that the organization should better publicise all of its services as most service users found out about the project through word of mouth or internet search. More information in clinic and through clinicians is recommended.

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